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AUTHOR Woods, Diane E., Ed.
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ABSTRACT

Two articles explore possibilities for collaboration between American and Asian researchers addressing disabilities in a worldwide context. The first article, by Mike Miles, is titled "Using Action-Oriented Disability Studies in Pakistan." It focuses on how information can be disseminated in informal, nontraditional (non-Western) ways. Action research is seen to offer relevancy to the needs of people with disabilities and professionals in developing nations such as Pakistan. Brief synopses of seven field studies in Pakistan are given, concerning mental handicap in the family, a survey of disabled children, development of a Child Developmental Skills Checklist, a survey of attitudes toward disability, a study of causal integration, community-directed rehabilitation, trends in polio paralysis, and ongoing information studies. This paper includes 12 references. The second article, by Judy Kuglemass and Kusdwiartri Setiono, is titled, "Developing Mutual Understanding between Western and Non-Western Cultures through Collaborative Research." It is based on a qualitative ethnographic study of Indonesian families with mentally disabled children, and stresses the importance of cross cultural collaboration of researchers. (DB)

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Special Issue in the series "The Changing Nature of Disability and Disability Awareness Worldwide"

The Potential for U. S. - Asia Research Collaboration: Two Examples

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Special Issue in the series "The Changing Nature of Disability and Disability Awareness Worldwide"

The Potential for U. S. - Asia Research Collaboration: Two Examples

This issue of INTERCHANGE is dedicated to exploring research and research possibilities in two Asian countries: Pakistan and Indonesia. This is intended to be an "installment" in a series dedicated to the theme: "The Changing Nature of Disability and Disability Awareness Worldwide."

The Miles article discusses several specific practical research projects that have been carried out in Pakistan. It is a shorter version of a paper published in 1991 in the *International Journal of Rehabilitation Research 14 (1) 25-35*. He especially pays attention to how the data can be disseminated in informal, non-traditional (in Western terms) ways. Miles, who spent nearly two decades living in Pakistan and working in the field of mental retardation, points out in the article that appears in this issue that "much basic, necessary research in special education and rehabilitation has been reported in the West, and is open for study in the Third World, yet it may lack impact on Government policy-making by not seeming relevant or by being reported in unfamiliar conceptual terms." He goes on to describe research that has been done in Pakistan and shows how "action-research" provides a relevancy to the needs of people with disabilities and professionals in Pakistan.

The Kugelmass-Setiono piece explores the relationship between Western and non-Western researchers and how collaboration can be developed in a sensitive and productive way. Kugelmass carried out a fellowship through the IEEIR in 1989 and her host/sponsor was Setiono, an Indonesian professor of Special Education. The two have continued to work collaboratively. They did a presentation at the 1991 Society for Disabilities Studies titled " The Integration of Western and Traditional Approaches to Disability Awareness and the Development of Culturally Appropriate Treatment Strategies." The article appearing in this issue of *INTERCHANGE* is a further development of that presentation.

Both articles provide the reader with a sense of the possibilities for cross-cultural, cross-national research and the development and promotion of disability awareness when close attention is paid to cultural needs and opportunities in collaborative endeavors. We would like to invite readers with relevant networks to propose, through the IEEIR fellowship program, studies which build on both themes presented in these two articles. **The Editor**

Using Action-Oriented Disability Studies in Pakistan

Mike Miles

Introduction

...Studies, at whatever level, are of little use if they remain inaccessible, but in Pakistan, the write-up and distribution of studies and materials in this field is generally weak. Aiming to do better, the MHC undertook studies that should be comprehensible to participants and potential readers ...The idea of disseminating information, i.e. giving away power, is strange. It is then agreeable to find oneself on the mailing list for regular, free infor-

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Developing Mutual Understanding Between Western and Non-Western Cultures Through Collaborative Research

Judy Kuglemass & Kusdwiartri Setiono

During the summer of 1989, through the support of a fellowship from the World Rehabilitation Fund, Dr. Judy Kugelmass investigated the relationship that exists between culture and family adaptation to disability in Bandung, Indonesia. Through in-depth interviews of fourteen families with children identified as"mentally handicapped" and participant observation in their homes, schools, and communities, this project hoped to inform rehabilitation practitioners about the significance of cultural considerations when working with children and families in the United States.

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mation that is relevant to one's work and is not intended to promote any equipment, drug, religion or political party...

...The difficulties of conducting rigorous research should not be allowed to prevent useful engagements in a secondary level of study. Also much needed are the cultural adaptation, translation and wider dissemination of existing know-how, including indigenous practices and the experience of people with disabilities, and augmenting the resources of junior professional workers who are often the sole, inadequately supported, interface between modern knowledge and the general public.

The MHC studies ...were done as part of a development movement, to see what was happening and what should be done next, to identify 'invisible resources', to facilitate policy development and to model a pattern of study with monitored follow-up

BACKGROUND

Special education and rehabilitation in Pakistan *are in their early stages*, but expanded appreciably after Government initiatives in 1985. Services are largely urban, institutional and focussed on children. Pakistan's population is 115 million (1991), of whom about 55 million are aged under 15. Some 27 million are getting education, but less than 15,000 have special needs specifically catered for. At least 250,000 children with significant disabilities are 'casually' integrated in ordinary schools. Urban hospitals provide some ear, eye and orthopedic surgery and rehabilitative aftercare for all age-groups. Some vocational rehabilitation is being attempted.

Little formal research has been done in special education and rehabilitation, and even less published. Postgraduate courses began recently at the National Institute of Special Education, Islamabad, the Education Department of Karachi University and Allama Iqbal Open University, Islamabad. The National Institute of Psychology, Islamabad, publishes some basic work in child psychology and assessment. Studies in pediatrics, orthopedics and psychiatry with peripheral bearing on rehabilitation have been published in reputable journals such as *J. Pakistan Medical Association, Pakistan Pediatric J., Pakistan J. Psychological Research* and in conference proceedings.

AIMS AND METHODS

Since 1978, Pakistani and expatriate staff of the Mental Health Centre (MHC) at Peshawar have engaged in several low-cost disability studies and made a sustained effort to disseminate the results and reflections widely. Earlier studies counted heads and dipped buckets to get an idea of 'what is there', to compare notes with other people's observations and to report to anyone who was interested. These studies advanced beyond a purely anecdotal level of evidence. Later studies involved more literature review and theoretical framework, but fell short of testing hypotheses with pre-validated instruments.

By Western standards, the feasibility of scientific rehabilitation studies in Pakistan appears small. Methodological rigour hardly seems appropriate, in the absence of elementary baseline data, of assistants with any research training, and of access to updated reference libraries or databases. What takes place in this situation has the nature of fieldwork and pilot study. However, the situation encourages innovation and unorthodox approaches, and the fields are not uncharted. Despite cultural differences, Western experience has some relevance.

Methodology should be within the researchers' operating capacity and likely to produce meaningful results. The MHC studies took place not to obtain an individual doctorate, nor to secure salaries for a research team, nor to prove the superiority of any particular theory, technique or ideology, nor to gather evidence to attack Government policy, nor merely to satisfy curiosity. They were done as part of a development movement, to see what was happening and what should be done next, to identify 'invisible resources', to facilitate policy development and to model a pattern of study with monitored follow-up. (It would, of course, be idle to deny any thought of personal benefit. Most social researchers hope to distinguish themselves by contributing original perspectives and to see their work used for the uplift of the masses.)

With very modest finance and academic resources, the MHC intended that its studies should increase access to good-quality information and should be open-ended to promote study and circulation of information. By formal research standards, the earlier studies were messy and semi-scientific. Quantitative results were few, but not all predictable. Well-controlled modern social research is neither easy nor perhaps even appropriate where there are very few organized systems to observe, where public thought appears to be largely pre-scientific and where demographic data is mostly guesswork. Rigorous research takes place in a different conceptual world to that of the Government junior planner or education director. It would normally fail to convey anything either intelligible or that might affect practice.

BRIEF SYNOPSES OF FIELD STUDIES

❖ ***Mental handicap in the family.*** In Peshawar in 1978, the concept of 'mental handicap' was familiar to only a few pediatricians, and then only in medical terms. There was no family guidance literature in local languages. There were three schools for mentally handicapped children in Karachi and one each in Lahore, Rawalpindi and Peshawar, run by voluntary agencies. Estimating that there must be at least 500 children with severe mental handicap among Peshawar's 300,000 population, MHC staff spent two weeks seeking some of these children through local informants and follow-up of old contacts. Staff aimed also to discover the attitudes of families towards their handicapped child, and to publicize MHC services. They found 20 mentally handicapped children, half of whom had additional serious disabilities.

A report on the children, families, awareness of mental handicap, attitudes and availability of information, was mailed to 100 psychiatrists, social workers, pediatricians, psychologists and special school managers already known to MHC staff. A medical newspaper published a digest of the report and an Indian journal published extracts. Many of the Pakistani readers had already received issues of a MHC newsletter about mental handicap and a MHC English-language advice pamphlet for families. This basic study used Pakistani staff in discovery and reporting, and was educative to them, to the families whom they found and also counselled, to the report writer and reader. It was not 'participatory research' in the sense of empowering families to re-evaluate and change their own world. Yet it was participatory in that Pakistanis at various professional and non-professional levels learned about mental handicap in their own society, and were able to reflect upon and communicate their discoveries to other interested people.

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❖ ***Survey of disabled children.*** The next study (1980) involved college students doing an obligatory 'social work' project. Several hundred students were briefed to survey 40,000 urban and rural households. They located 1,536 children or young people with disabilities and asked about their lives, needs and hopes. The costs were around US $200.[8] for printing forms and mailing a detailed report to 200 concerned people in Pakistan and abroad. A digest was presented at an Asian disability congress. One of this study's aims was to substitute names and details for statistical guesswork. During IYDP, the Government had wanted to "do something for the people with disabilities" but did not know where to begin. The MHC study produced detailed information on the situation of many disabled children, and offered low-cost, feasible recommendations. Some of the colleges with students who carried out the survey did further studies, and the students learned something of the social realities of having a disability.

Giving study results to the Government was not difficult. The Provincial Education Secretary, who authorized student involvement, was keen to see the report. The Social Welfare Directorate wanted detailed results to help design IYDP programs. The report was mailed to dozens of Federal Government officials listed in the phone book. In a largely pre-literate society where information media are closely supervised, free hand-out of a genuine fact-finding study is rare. The report reached Government at a time when it was interested in disability and needed facts.

...Pakistanis at various professional and non-professional levels learned about mental handicap in their own society, and were able to reflect upon and communicate their discoveries to other interested people.

❖ ***Child Developmental Skills Checklist.*** Needing appropriate developmental checklists for use in special schools, family counselling and home education, the MHC staff met weekly to revise European material. Personal experiences of child-raising were pooled with professional observation of pupils in the classroom. Non-teaching staff took part, e.g. a driver with a large family in his Pakhtun village south of Peshawar, a physiotherapy assistant raising six children in another village and, a classroom assistant who raised four children in a minorities slum. Broad staff participation made the outcome more meaningful for families from many backgrounds and cultural practices. The teachers gained confidence to make further periodic revisions, when they realized that the checklists were not simply given 'from above' but were actually based on experience. A revised Urdu version has been widely used in special schools and a second revision was published in 1991.

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❖ ***Attitudes towards Disability.*** In 1981, the National Council of Social Welfare, Government of Pakistan, gave the MHC $3,000 to "do some research on disability". The first sponsored study surveyed public knowledge and attitudes toward disability, and enquired whether media coverage of IYDP (1981) was able to be recalled a few months later, by structured interviews with 286 urban and rural people. The report (Miles, 1983) also reviewed the largely anecdotal literature on African and Asian attitudes towards disabled people. The report appended extensive quotations to facilitate further work, and outlined possible college-level studies. The MHC printed and distributed 500 copies internationally to people and organizations actively concerned with Third World disability. The report was added to the Library of Congress and ERIC. Digests were read at national conferences. The report is used as a textbook in several European universities and more recently Pakistan. A later reprint of 500 copies was financed by NOVIB and UNICEF.

Pakistan's Minister for Information, receiving the report, instructed the Peshawar television station to do a program on the topic which was shown nationwide at prime time. Radio scripts on disability and basic rehabilitation, written at the MHC in 1984 after the attitudes report, have been broadcast in at least ten languages and used in training Afghan health workers. After five years' delay, the Government implemented two of the report's three main recommendations, i.e. to hold a national workshop on attitudes, disability and media (Kolucki et al, 1990) and to plan a national disability information centre.

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❖ ***Casual Integration.*** A second Council-sponsored study investigated children with disabilities in ordinary schools. Teachers in 103 primary and secondary schools of the North West Frontier were asked if any of their pupils were disabled. From 43,416 enrolled pupils, 825 (1.9%) were reported. Disability was verified by the investigator. The pupils were interviewed about how they got along in school. An interim report was circulated and a Society for Integrated Education of Handicapped Children was formed which employed social workers to follow up these pupils and to involve more schools in practical integration.

Education officials trying to extend special education were merely confused by the idea that thousands of disabled children were already casually mainstreamed. Six years later, official interest in educational integration has begun to pick up.

Five hundred copies of the final report (Miles, 1985a) were mailed to a growing list of interested parties. The report, discussing many aspects of educational integration and practical classroom strategies, is in the ERIC database. An Argentine

parents society asked to translate it into Spanish. Digests of the study were read at conferences and appeared in an African journal. Oxfam sponsored a reprint of 400 copies. A UNESCO consultant used the study at a workshop in Ecuador. In 1988, UNICEF sponsored 500 more reprints for inservice training of primary teachers in Sind Province. Several university courses use the report as a set text or recommended reading. However, the effect on the Government of Pakistan was minimal at the time. Education officials trying to extend special education were merely confused by the idea that thousands of disabled children were already casually mainstreamed. Six years later, official interest in educational integration has begun to pick up.

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❖ ***Community Directed Rehabilitation.*** Various community rehabilitation strategies were field-tested in developing countries in the 1980s. The MHC was the resource base for community mobilization, planning and training staff for new centres run by autonomous local associations in ten towns within 200 miles of Peshawar between 1979 and 1987. Four special schools were started and are still working, and nine physiotherapy centres, of which six continue. All the other MHC study topics contributed to this ongoing mobilization exercise and were in turn field-tested or exercised in these locations. The experience gained has been reported in several publications (e.g. Peters & Rehman, 1989; Miles, 1990a).

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❖ ***Trends in Polio Paralysis.*** The high profile of post-polio paralysis at the MHC physiotherapy clinic, despite immunization campaigns, led to the comparative study of data on polio and cerebral palsy from six institutions in Pakistan and India (Miles, 1989a & forthcoming). The relatively constant incidence of cerebral palsy gave a surrogate indication of clinic utilization, enabling the interpretation of clinic polio data in terms of trends. Centres at Quetta, Lahore, Kohat, Mingora and Calcutta pooled data annually, coordinated by the MHC. This sort of 'district reporting' and 'sentinel surveillance' is a key part of the World Health Organization strategies for the global eradication of polio.

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❖ **On-Going Information Studies**. Other MHC studies of low-cost vocational rehabilitation, development issues for mental handicap associations, religious resources for attitude change, transfer of cerebral palsy handling skills (Miles & Frizzell, 1990), have been circulated in similar ways or are in progress. Arising with this formal and informal dissemination, was a growing awareness that information is vital to policy and service development in "Third World rehabilitation" (Miles, 1985b p.38-47; 1989b, 1990b,). These studies were ancillary to the main work of the MHC, which was to provide special education, counselling and physiotherapy, to publish relevant literature and to act as a resource and training base for rehabilitation development.

DISSEMINATION METHODS

Studies, at whatever level, are of little use if they remain inaccessible, but in Pakistan the write-up and distribution of studies and materials in this field is generally weak. Aiming to do better, the MHC undertook studies that should be comprehensible to participants and potential readers, and hopefully also interesting. This required that MHC staff should already be active in practical service and policy development and that study recommendations should be feasible and attractive. There was early planning of how the study results would be communicated, to whom, in what quantity, and to what end. This communication aim was part of a process. Many recipients of study reports were already getting MHC newsletters and counselling materials and meeting MHC staff at national conferences. Some credibility had accrued.

We began with informal print publication. Our presentation was poor, e.g. cyclo-styled foolscap with 750 words per page to reduce costs. Complaints from Westerners led to some modifications, and word-processors reached Peshawar in the mid-1980s, facilitating page design. If readers expect worthwhile contents they may tolerate poor appearance in documents from Pakistan. However, the MHC slowly improved presentation, without incur-

Arising with this formal and informal dissemination, was a growing awareness that information is vital to policy and service development in "Third World rehabilitation"

Pakistan abounds in cheap photocopiers; books and journals that arrive from the West are thus assured of many extra copies

ring heavy costs. Western professionals struggle with too much information, so unsolicited mailed reports may not be welcome. By contrast, information sources are few in Pakistan and many other countries. The idea of disseminating information, i.e. giving away power, is strange. It is then agreeable to find oneself on the mailing list for regular, free information that is relevant to one's work and is not intended to promote any equipment, drug, religion or political party.

FORMAL PUBLICATION

Formal publication could be either in book form or by academic journal. However, book publication is ruled not by the needs of the rehabilitation field but by market forces. The delays of formal publication would also make the studies less useful as catalysts for change. Therefore, the MHC policy has first been for free, informal distribution, aided by grants from NOVIB, Oxfam, UNICEF and Christoffel Blindenmission. Not-for-profit publication is now being considered, using desktop publishing software to control costs up to camera-ready manuscript.

Professional rehabilitation journals do not exist in Pakistan. Some low-circulation newssheets and semi-popular journals have published digests of MHC studies. They tend to carry papers that would not be accepted by peer-reviewed international journals. For the sake of one's career, Third World professionals try for publication in reputable journals, which are affordable by only a few university libraries. If successful, their work leaves the country and little returns. Journals of their own country get digests and left-overs. However, urban Pakistan abounds in cheap photocopiers; books and journals that arrive from the West are thus assured of many extra copies. In recent years, library services circulating academic 'current contents' have also improved, with central copying of papers requested by subscribers.

MULTI-LEVEL APPROACH

In Pakistan there is a shortage of training and experience for carrying out good quality research, of finance to pay for and disseminate it and of people with the time to read it, and acumen to grasp its importance, or the political clout to take action. Downmarket, at the level of the MHC work, bright people are still needed to do useful studies and to appreciate the results, but formal training is not obligatory. There are more participants, lower costs, greater accessibility, more immediate application. Admittedly, there is also more risk that flawed conclusions may be drawn and prejudices reinforced rather than challenged. At the popular level, people do learn by experience but lack critical and comparative faculties and have limited information horizons.

The gap between the academic and the popular worlds, in the social sciences, may be largely one of language and concept. Academics can use popular language when they choose, e.g. when talking to their children. The highly specific and differentiated jargon of academic discourse is justifiable as a time-saving device, though often used merely for mystification. A median between popular and academic discourse can often be found, with some effort of drafting and re-drafting. If academics believe that the ordinary tax-payer should finance their research through Government grants, there is perhaps some responsibility to communicate the results in terms accessible to the public.

There is not yet an academic jargon of special education and rehabilitation in Pakistan, but the language of educated people (English) is inaccessible to the masses. The MHC therefore published the first Urdu-language manuals on education of children with mental handicap (a translation of English material written in Pakistan), visual or hearing impairment (translations of material written by Europeans with Third-World experience) and on basic physiotherapy (some original Urdu material and some translated Western material), making this knowledge available to Pakistanis with secondary-school literacy. This exercise has begun preparing readers who should be able to understand the language and concepts of special education and rehabilitation studies when such studies become available in Urdu.

IN CONCLUSION

Much basic, necessary research in special education and rehabilitation has been reported in the West, and is open for study in the Third World. Yet it may lack impact on Government policy-making by not seeming relevant or by being reported in unfamiliar conceptual terms.

Many Third World Governments are making the same mistakes as Western Governments of 30 or 50 years ago. Alternatively, these may be seen not as mistakes but as service provisions congruent with the *present stage* of attitudinal, educational and economic development (Miles, 1989c). Access to Western knowledge may speed the evolution of attitudes and service provisions, blocking blind alleys and spending less time on detours if the exposure to this knowledge is managed in a way that makes it credible and attractive.

To make the available knowledge intelligible, interesting and relevant to generalist planners and mid-level professionals, in Pakistan or elsewhere, it may be contextualised in action-oriented studies, mini-surveys and reported observations. Reports can be disseminated by direct mail, semi-professional journals and other media. The difficulties of conducting rigorous research should not be allowed to prevent useful engagements in a secondary level of study. Also much needed are the cultural adaptation, translation and wider dissemination of existing know-how, including indigenous practices and the experience of people with disabilities, and augmenting the resources of junior professional workers who are often the sole, inadequately supported, interface between modern knowledge and the general public.

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As is often the case in qualitative/ethnographic research, particularly when an investigator enters a society quite different from her own, this researcher learned a good deal more than that which was anticipated. Of particular significance were the implications that emerged for applied researchers in rehabilitation or other human service endeavors in economically underdeveloped, non-western societies.

The findings of Dr. Kugelmass' report to the World Rehabilitation Fund focused on the existence of an indigenous system of caring that provided children with environments that maximized their functioning while providing support to their families. Although the formal educational and medical systems provided many services to the families interviewed, these were not perceived by parents as psychologically supportive. Instead, emotional as well as material support came primarily from extended family and local community networks and a belief system that focused on the importance of acceptance and patience that comes out of the religious beliefs and culture found in western Java. Although it was clear that the families interviewed were not representative of all Indonesian families or even of all families in Bandung that had children identified as " mentally handicapped," their ability to adapt successfully was seen as a function of their reliance on both formal and informal support systems.

These families did not, however recognize the significance of their religious and cultural traditions in their adaptations to their child. Parents and professionals consistently articulated their need for Western institutions and technology in order to more adequately meet the needs of their children. There was no apparent recognition that the most effective teaching and parenting strategies mirrored culturally appropriate interactions and the spiritual beliefs on which they were based. Dr. Kugelmass concluded that this lack of awareness was limiting opportunities for optimal and inexpensive treatment and education within the existing cultural context. The reliance on technological solutions to human problems that characterizes Western medicine and the looking towards the West for solutions by economically underdeveloped countries was pointed to as one source of this dilemma. The report advised American and Indonesian professionals to adopt an ecological framework in order to discover the strengths and sources of support that exist within their own societies, communities, and families when developing service plans for children with disabilities.

Although both Dr. Kugelmass and Dr. Setiono met frequently in Indonesia, it was only through subsequent consultation and shared reflections...that both researchers came to a deeper understanding of the implications of these findings.

The dichotomy that exists in the attitudes many Indonesians hold towards Western versus traditional values and institutions must be considered when offering interpretations to applied research and in offering suggestions for service-delivery models.

Dr. Kusdwiartri Setiono, Professor of Developmental Psychology and Dean of the Faculty of Psychology at the Padjadjaran University was a primary collaborator for this project. Although both Dr. Kugelmass and Dr. Setiono met frequently in Indonesia, it was only through subsequent consultation and shared reflections in preparation for the presentation at the national conference of the "Society for Disability Studies" in Oakland, California in July, 1991 that both researchers came to a deeper understanding of the implications of these findings. Dr. Setiono was appreciative of the insights that Dr. Kugelmass' research offered into developing culturally appropriate and affordable special education and rehabilitation services in Indonesia. However, she felt that the conclusions of the research did not take other realities that exist in her country into account.

There was no disagreement that a philosophy of life basic to Indonesia is one of acceptance, demonstrated in the patience and warmth that characterizes the interactions between parents and children. Certainly, the social and emotional development of most

children is enhanced through this kind of care. However, as Dr. Setiono pointed out, acceptance is not a wholly positive characteristic, either for Indonesian society or for children with disabilities. The religious origins of this philosophy are rooted in the belief that acceptance is a demonstration of faith that all reality comes from God and is to be faced with patience and understanding. It is also a belief system reinforced by the long colonial history of Indonesia.

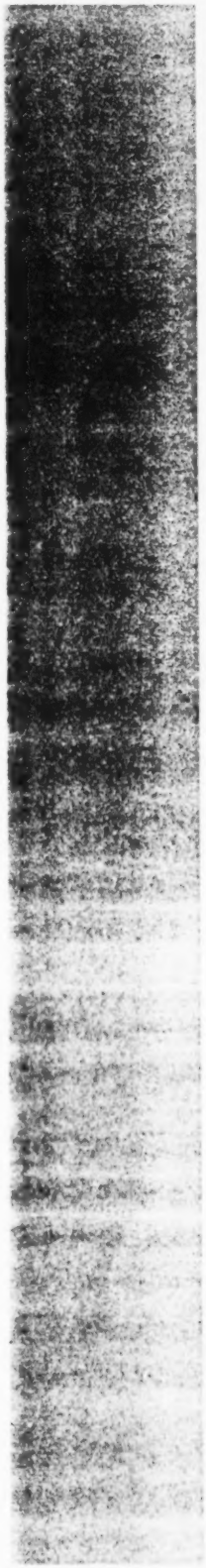
Dr. Setiono believes that in order to achieve economic progress, Indonesians need to modify their belief system and become more active in shaping their own destiny. Similarly, acceptance can have a negative aspect when exaggerated by parents of children with or without disabilities. Examples of negative demonstrations of acceptance cited by Dr. Setiono and observed by Dr. Kugelmass in Indonesian parents of children with disabilities include giving the child whatever he or she wants; not limiting behavioral excesses; failing to systematically instruct the child in new behaviors or skills; not seeking outside, professional assistance.

Although the parents in Dr. Kugelmass' study represented a wide range of social class and educational backgrounds, none were from among the poorest in Indonesian society, and all had some degree of education. All the parents interviewed had sought help for their child from both "traditional," i.e., indigenous, and modern, i.e., Western based, services. Dr. Setiono believes that this demonstrated the importance of and possibility for modification of the philosophy of acceptance to include seeking help for your situation from those that exist around you. Such modification has come about through education and parents' understanding of the nature of disability. Among less educated people, particularly those in rural areas with limited access to outside information, the response to having a child with a disability is often quite different. Frequently, one of two extremes are seen: 1. The child is perceived as evidence of God's blessing and is responded to by treating the child as an honorable or saintly person. 2. The child's existence or disability is denied and he/she is kept hidden from extended family, friends, and neighbors, or unrealistic expectations/demands are placed on the child.

Another aspect of the research findings expanded upon through collaboration was the nature of the role of professionals in providing services to families with disabled children. Certainly there will never be enough doctors, psychologists, therapists, and teachers to meet all the needs of families in either Indonesia or the United States. Many Western countries are addressing this reality through a movement toward treatment teams that include paraprofessionals and parents. Self-help groups and the empowerment of "consumers" is another aspect of that movement. Although such an approach appears to be one that would meet many of the needs of a country such as Indonesia, the roles assigned to professionals and others in perceived positions of authority as well as the social class distinctions that currently exist present substantial barriers to providing services in this way. Although indigenous support systems exist at all levels of Indonesian society, unless there is a person or people in position of authority perceived as "in-charge" or "honorable," the information received and the advice given are not valued. Therefore, if a team approach or the use of informal systems are initiated, particularly in rural areas and among poorly educated people, a person with perceived authority must not only be in charge, but may need to offer the information directly to parents if it is to be perceived as true and therefore worthy of consideration.

Although indigenous support systems exist at all levels of Indonesian society, unless there is a person or people in position of authority perceived as "in charge" or "honorable," the information received and the advice given are not valued.

Physicians and other rehabilitation professionals must therefore identify and collaborate with individuals perceived as



The collaborative relationship is more than the key informant/ researcher relationship typically seen in ethnographic research.

holding positions of authority within traditional communities. Attempts at developing collaborations between physicians and "dukuns," i.e., the traditional healers that are respected and consulted by Indonesians from all levels of society, are being initiated. However, in spite of the fact that all Indonesians, including physicians, consult dukuns on personal health and spiritual matters, there appeared to be a resistance to public acknowledgement of this relationship among many of the professionals interviewed in Bandung. The resistance to open collaboration with dukuns can also be seen as reflecting the ambivalent attitude towards indigenous practices that comes from a colonial history. Although it seems paradoxical that a colonial past would limit Indonesians' willingness to become involved with traditional Indonesian practices, it is one of many examples of the love-hate relationship that exists between Western ideas and traditional Indonesian society. Although Western goods, services, and technologies represent the colonial past to some, they also offer the promise of technological and economic development.

The response to Western versus traditional ideas and practices varies throughout the country, and depends a good deal upon the ethnic history of the Indonesian people in question and their social class. Upper-class and professional Javanese and Sudanese people, as represented in Bandung, although proudly Indonesian and devotedly Islamic, have either been educated and trained in Europe, or received education and training in Indonesia based on a European model. Ethnic groups from other islands in the Indonesian archipelago are less connected culturally with the West, and so are less reluctant to identify themselves with non-Western traditions and institutions, such as the use of traditional medicine. These differences, and the dichotomy that exists in the attitudes many Indonesians hold towards Western versus traditional values and institutions must be considered when offering interpretations to applied research and in offering suggestions for service-delivery models.

IN CONCLUSION

These expanded interpretations of the data from Dr. Kugelmass' study came about through the in-depth collaboration that occured between herself and Dr. Setiono. These modifications have certainly added to our understanding of what will be necessary in the development of services for children and families in Indonesia. Its significance also lies in the recognition of the importance of working collaboratively with a well-informed, local researcher such as Dr. Setiono, when conducting research in cultures other than one's own. This would be true between cultures as disparate as the United States and Indonesia, or within a sub-cultural group within one's own country. The collaborative relationship is more than the key informant/researcher relationship typically seen in ethnographic research. Rather, an ideal collaboration exists when two researchers interested in exploring similar issues work together, both bringing research and content area expertise to the work, each intimately familiar with her own culture, and knowledgeable enough of her partner's culture so that each is aware of the biases the other may bring. The collaboration should include research design and implementation, as well as the interpretations and implications of the results. Most importantly, the collaborative relationship must be characterized by trust and mutual respect for the perspectives of the other. The mutual understanding that results will benefit both the researchers and their respective societies.

❖ ❖ ❖

IEEIR Project Director Joins NIDRR India Team

The National Institute for Disability and Rehabilitation Research (NIDRR) which has an ongoing consultative relationship with India's Ministry of Welfare sent a team of ten U. S. disability consultants to India to participate in a training and evaluation consultancy for the District Rehabilitation Center (**DRC**) Scheme in India (see ***INTERCHANGE*** Spring 1990 for a report on the DRC Scheme.)

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❖ Paul Ackerman of NIDRR coordinated the activities of the team led by William Graves, NIDRR's director. The eight trainer-evaluator participants included:

❖ Ms. Celane McWhorter, Director, Office of Government Relations, Assoc. Persons with Severe Handicaps;

❖ Christine Y. Mason, Ph.D., Director, Community Employment Projects, National Assoc. of Rehabilitation Facilities;

❖ Corinne Kirchner, Ph. D., Director, Social Research, American Foundation for the Blind, Inc.;

❖ Marvin Efron, O.D., Ph.D., Optometrist;

❖ Janet M. Williams, MSW, former Co-Director, Community Partners, Beach Center for Families and Disability;

❖ Joan M. Patterson, Ph. D., Asst. Professor, School of Public Health, University of Minnesota;

❖ Ms. Ellen L. Blasiotti, Chief, Information, Dissemination and Utilization Program, NIDRR; and

❖ Ms. Diane E. Woods, IEEIR, Project Director.

After spending several days in Delhi meeting with US Embassy and Ministry of Welfare officials and key players in the DRC scheme in India, as well as the directors of the National Institute of Mental Handicaps and the National Institute for Visual Handicap in preparation for the training and evaluation site visits, two teams of four spent a full week working with folks who are trainers in the DRC scheme. The

INDIAN VILLAGE: DRC Rehabilitant (popcorn vendor)

DRC outside Madras

NIDRR consultants also learned about the facilities of the National Institute on Visual Handicaps firsthand in Deradun and the National Institute of Mental Handicap in Secunderabad, and the people associated with those facilities, by spending four intensive days consulting in each of these institutes.

To help the U. S. team understand better the needs of Indian villagers and the problems in the delivery of services in very rural areas, all team members visited at least one village for a day and some of the team members had the opportunity to visit another village for another full day. The village visit gave the NIDRR team members an opportunity to see the DRC team members at work in the village setting and to see some vocational rehabitants, as well as children with disabilities who were receiving some services from the scheme. What we noticed was that although the DRC ideally is a community based program, it tends to be influenced heavily by the medical model, with a top down approach rather than the other way around.

Since the team was asked for a report and recommendations, among other things, we strongly urged that the needs of the villagers with disabilites be met through shifting emphasis to village-generated, short-term intensive services.

It is amazing how much more culturally sensitive Western disability specialists can become by allowing themselves the opportunity of observing village life in non-Western developing countries. The experience was incredible and because the IEEIR project director has had this first hand sensitizing experience with India and has developed new and fostered old contacts, she will be encouraging U. S. disability specialists to look at India for possible fellowship exchanges in the future.

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Interchange: a publication of the International Exchange of Experts and Information in Rehabilitation (IEEIR), a project funded by the National Institute of Disability and Rehabilitation Research to the World Rehabilitation Fund, Inc., and subcontracted to the University of New Hampshire's Institute on Disability.

The purpose of the IEEIR is to provide opportunities for the U. S. disability community to become more aware of developments in Asia, the Pacific, and Africa through fellowships awarded to U.S. disability specialists, publications prepared by foreign experts, and through conferences and meetings. **Interchange** is another way of sharing information about the IEEIR on international developments. For more about the Project, write or call:

IEEIR 6 Hood House
University of New Hampshire
Durham, NH 03824
Tel: (603) 862-4767 Fax: (603) 862 4217

Editor: Diane E. Woods
Typesetting, Graphics, Co-Editor: Richard Melanson

Fellowship application information

THE WRF-UNH-IEEIR will make ten awards a year for the three years of the project period (9/30/90-9/29/93). Anyone interested in applying must be a U.S. citizen, should have a "track record" in his/her disability discipline, be open to new ideas, and be in a position to influence policy and/or practice here in the U.S. It is a plus if the individual applying has some knowledge of another culture since the fellowships are brief (3-5 weeks) and previous experience would be helpful. An application for an IEEIR fellowship has to be focused in such a way to get the most out of a short period of time. Evidence of host arrangements must be shown in the application. Federal employees are not eligible for fellowships. People with disabilities are encouraged to apply.

Fellowship application deadlines

- January 15, 1992
- April 15, 1992
- July 15, 1992
- October 15, 1992

To obtain a fellowship application contact:

Diane E. Woods, Project Director, IEEIR

UNIVERSITY OF NEW HAMPSHIRE
International Exchange of Experts and Information in Rehabilitation
Institute on Disability
6 Hood House
Durham, NH 03824

8 - 01170

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